

Final Report & Recommendations



Missouri Alzheimer's State Plan Task Force

Report to Governor Jeremiah W. (Jay) Nixon and the Missouri General Assembly

December 2012



OFFICE OF THE LIEUTENANT GOVERNOR

STATE OF MISSOURI
JEFFERSON CITY

65101

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October 31, 2012

The Honorable Jeremiah W. Nixon,
Missouri State Capitol, Room 216
Jefferson City, Missouri 65101

Dear Governor Nixon:

As Chairman of the Missouri Alzheimer's State Plan Task Force, I am pleased to submit to you our Final Report and Recommendations. The Task Force was created in 2009 by the Missouri General Assembly to address the current and future impact of Alzheimer's disease and related dementia in Missouri. According to its enabling legislation, the final day of the Task Force is November 1, 2012. As such, we are submitting this Final Report for your review.

I am honored to have served as Chairman the past three years and to have worked with this talented and committed team of individuals. The Task Force's State Plan was first submitted to you and the Missouri General Assembly in November 2010. The State Plan assessed the impact of Alzheimer's disease and related dementia issues on Missouri residents and included recommendations for responding to this very serious public health matter. In February of this year, the Task Force submitted our 2012 Supplement to you and the General Assembly. The Supplement contained updates to the statistical and legislative data in the State Plan and set forth our updated recommendations. Our Final Report focuses on the steps that we believe are most crucial for effectively combating and preventing Alzheimer's disease in Missouri.

Thank you for your consideration of this very important issue to our state. Please do not hesitate to let me know if I or the other Task Force members may be of further assistance as you review our Final Report and Recommendations.

Sincerely,

A handwritten signature in black ink that reads "Peter Kinder".

Lt. Governor Peter Kinder
Chairman, Missouri Alzheimer's State Plan Task Force

MISSOURI ALZHEIMER'S STATE PLAN TASK FORCE
MEMBERSHIP

Chairman

Lt. Governor Peter Kinder

Pam Dixon

Lt. Governor's Designee

Margaret Donnelly

Director, Health & Senior Services

Ellie Glenn and Glenda Meachum-Cain

Health & Senior Services Designees

Keith Schafer

Director, Mental Health

Jan Heckemeyer

Mental Health Designee

Ronald Levy

Director, Social Services

Kristen Edwards

Theresa Valdes

(retired, April 30, 2012)

Social Services Designee

Senator Maria Chappelle-Nadal

House of Representatives Member

Senator Bill Stouffer

Missouri Senate Member

Gwendolyn Richards

Member with early-stage Alzheimer's
or related dementia

VACANT

Maureen Dempsey (resigned Nov. 1, 2010)

Member who is a family caregiver of a person
with Alzheimer's or a related dementia

Dr. John Morris

Member who is a licensed physician with
experience in the diagnosis, treatment,
and research of Alzheimer's disease

Carol Scott

Member from the office of the state
ombudsman for long-term care facility residents

Lisa Baron

Member representing the home care profession

Timothy Dolan

Member representing residential long-term care

Deborah Ellis

Member representing the adult day
services profession

John Huff

Member representing the insurance profession

Molly White, Designee

Jean Leonatti

Member representing the area
agencies on aging

Joseph Palm

Member with expertise in minority health

Lois Zerrer

Member who is a licensed elder law attorney

Clara Carroll Rodriguez

Member from the leading voluntary health
organization in Alzheimer's care, support,
and research

Joan D'Ambrose

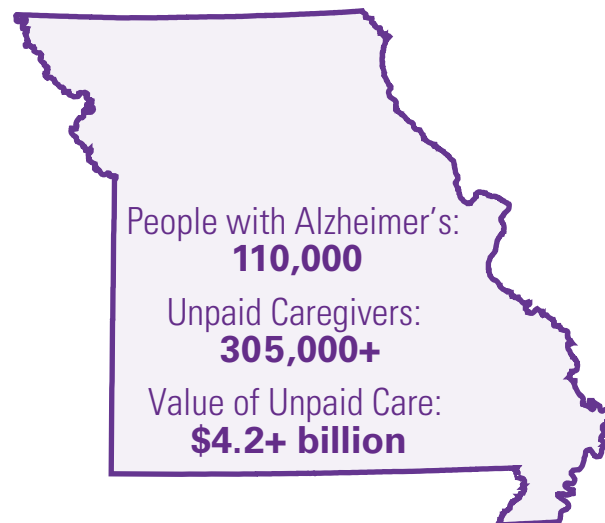
Member from the leading voluntary health
organization in Alzheimer's care, support
and research

MISSOURI ALZHEIMER'S STATE PLAN TASK FORCE -THE PAST THREE YEARS

Alzheimer's disease is a health crisis that affects all classes of people across all regions of our country. There are 5.4 million Americans living with Alzheimer's – 110,000 in Missouri. Those numbers will rise exponentially with the aging of the baby boomers. More than 130,000 Missourians are expected to have this disease by 2025 unless we find a cure.

Alzheimer's is life threatening, prevalent and costly. The direct costs of caring for those with Alzheimer's will total an estimated \$200 billion in America by the end of 2012, including \$140 billion in costs to Medicare and Medicaid. The average per person Medicare cost is three times higher for someone who has Alzheimer's or related dementias than someone who does not, and the Medicaid spending is 19 times higher.

ALZHEIMER'S IN MISSOURI



The Missouri Alzheimer's State Plan Task Force was commissioned three years ago to address the Alzheimer's crisis in our state. The 19 member task force convened community forums to hear the concerns of Missouri citizens across the state, including individuals living with the disease, family caregivers, and key stakeholders. Hundreds of people spoke honestly, passionately and courageously about how Alzheimer's has forever changed their lives. They voiced concerns about the difficulty of getting an appropriate diagnosis, the physical, emotional, and financial hardships of caregiving, the need for quality dementia care, the desire to keep loved ones at home, and the importance of more support for research to find a cure.

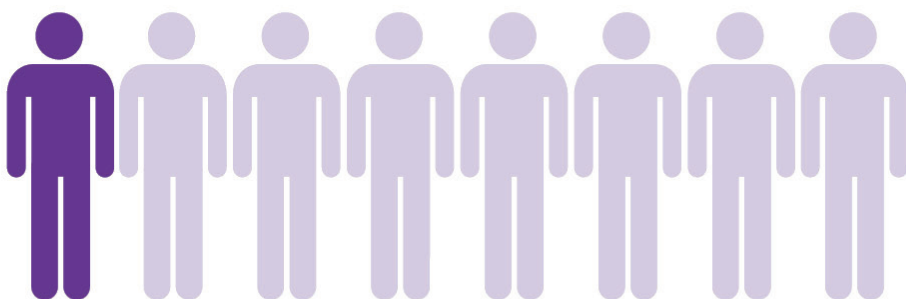
In November 2010, the Task Force published a State Plan for combating Alzheimer's in Missouri that addressed the above concerns raised at the forums. A Supplement to the Plan was released by the Task Force in February 2012 and contained updated statistics and goals. The Task Force has continued working diligently with various state leaders, departments and agencies to find the most effective ways to address Alzheimer's in Missouri. Although much still needs to be done, numerous advancements have been made on both the state and federal level, including:

- Missouri developed a unified system of screening, referral, and care planning for Missouri citizens with dementia. Funded by the Administration on Aging, this statewide project leveraged partnerships between the Department of Health and Senior Services, Area Agencies on Aging, and the Alzheimer's Association to advance better access to detection and community support.
- Federal funding is helping Missouri place an increased focus on home and community long term care options through implementation of the Balancing Incentives Payment Program and Money Follows the Person Demonstration Grant.
- The Center for Medicare and Medicaid Services (CMS) demonstrated their commitment to advancing quality dementia care by launching new training requirements for nursing home staff and releasing a free dementia training toolkit. Concurrently, the Department of Health and Senior Services is reviewing dementia training regulations to ensure consistency for all provider groups.

- Missouri is viewed as a world leader in Alzheimer's research with more than \$22 million in federal and foundation grants awarded in 2011. Additionally, legislation was passed in 2012 that will increase the one year pilot grant awards when state funding for Alzheimer's research is restored.
- By far the greatest achievement was the release of the first National Alzheimer's Plan in May of 2012. The plan calls for increased support for research, awareness, education and outreach, and caregiver support. These goals mirror those outlined in Missouri's State Plan.

The following recommendations contained in this Final Report seek to further advance these initiatives and keep Missouri as a leader in addressing the Alzheimer's crisis.

1 IN **8**
AMERICANS OVER
THE AGE OF 65 HAS
ALZHEIMER'S DISEASE



SIX RECOMMENDATIONS OF THE TASK FORCE

1. Increase Use of the AD-8 Dementia Screening Tool (AD-8)

The Task Force strongly recommends the use of the AD-8 as a consistent assessment tool to identify individuals who may be in early stages of dementia.

In Missouri, Project Learn MORE (funded by the Administration on Aging) has enabled the Department of Health and Senior Services – in partnership with the Alzheimer’s Association Chapters and the Area Agencies on Aging (AAAs) – to implement the program targeting undiagnosed and newly diagnosed individuals in the early stages of dementia, with a focus on low income, rural and minority populations. As of September 2012, the AAAs had screened a total of 3,831 referrals. New clients receive an AD-8 initial assessment and then have a six-month follow-up screening.

The AD-8 tool, developed by James E. Galvin, MD, and colleagues at Washington University, provides a mechanism to determine if an individual is experiencing any changes in memory, problem-solving abilities, orientation, and daily activities.ⁱ The AD-8 is a quick, accurate and easy tool to use. If individuals are found to display symptoms of dementia through the AD-8 screening, they and their families are connected to supportive community-based services such as educational classes, respite, support groups and volunteer opportunities. This program has strengthened partnerships among the AAAs, Alzheimer’s Association Chapters, senior centers, physicians, and other professional care providers by establishing a unified system of screening, referral, care planning and supportive services to individuals with Alzheimer’s and related dementias.

2. Advance Missouri as a Leader in Delivering Improved Dementia Care

The Task Force strongly recommends the implementation of innovative programs to provide quality dementia care.

Missouri is moving forward with the implementation of three new initiatives designed to improve the delivery of quality dementia care for individuals living in long term care communities.

In September of 2012, The US Department of Health and Human Service Centers for Medicare/Medicaid (CMS) awarded the Interdisciplinary Center on Aging (ICOA) at the University of Missouri nearly \$15 million in grant funding for “Missouri Quality Initiative for Nursing Homes” as part of the Initiative to Reduce Avoidable Hospitalization among Nursing Facility Residents. This demonstration project aims to reduce re-hospitalization of nursing home residents in the St. Louis region which has been identified as having one of the highest re-admission rates in the country.

Also in the fall of 2012, CMS made available to every nursing home in the country a dementia training toolkit, Hand and Hand: A Training Series for Nursing Homes. The free seven part series is designed to provide nursing homes with a high-quality training program that emphasizes person-centered care in the care of persons with dementia and the prevention of abuse.

Dementia Care Mapping (DCM) is a method of evaluating the delivery of person-centered care and to improve the quality of care delivered to persons with dementia living in long term care communities. DCM provides valuable, clear and reliable information for both those who provide dementia care and those who receive it. Although widely used across Europe, DCM is still relatively new to the United States. In 2012, Missouri hosted DCM training for professionals and is quickly becoming a nationwide leader in the implementation of DCM.

3. Keep Funding Missouri as a Leader in Alzheimer's Research

The Task Force strongly recommends the restoration of appropriations for the Alzheimer's and Related Disorders Research Program to help Missouri continue to be a world leader in Alzheimer's research.

The Alzheimer's Disease and Related Disorders Research Program, established by legislation in 1987, focuses on advancing new research initiatives for Alzheimer's and bringing new researchers into the field. The program is administered by the Board of Curators at the University of Missouri and has been extremely successful. Unfortunately, since 2005 this program has had no appropriations from the state.

In 2012, the General Assembly passed Senate Bill 563, which increases the one year pilot grant awards for individual Alzheimer's research from \$30,000 to \$50,000. This increase will enable Missouri to continue to produce novel research on Alzheimer's disease from world-renowned experts. Now that Senate Bill 563 has been signed into law by the Governor, it is crucial that the funding for this program be allocated to the University of Missouri Board of Curators.

4. Division of Assets for Individuals with Younger Onset Alzheimer's

The Task Force strongly recommends the Missouri Departments of Health and Senior Services, Social Services, and Mental Health work together to research the costs and benefits of allowing for Division of Assets for married individuals who qualify for long term care services regardless of the care setting.

In order to prevent "spousal impoverishment", the "division of assets" procedure alters the MO HealthNet eligibility requirements for couples in a situation where only one spouse is in need of skilled nursing home level of care. Under division of assets, the spouse needing care can receive MO HealthNet without the spouse at home being required to spend nearly all of the couples' assets or being left with insufficient funds to pay monthly bills.

Currently in Missouri, if an individual is under the age of 63, is married and has younger-onset Alzheimer's, he or she must receive care in a skilled nursing facility in order for the couple to qualify for division of assets. The spouse needing care is unable to stay in the community and receive Home and Community Based Service programs normally accessible to persons who can be safely cared for at home. The Task Force recommends that the State assess the costs and benefits of allowing married couples to utilize the division of assets procedure if the spouse needing care is under the age of 63 and would otherwise qualify for long term services caused by the onset of Alzheimer's disease.

5. Enhance Access to Home and Community Based Services for Individuals with Alzheimer's

The Task Force strongly supports a review of other states that have implemented a consumer directed services (CDS) policy allowing individuals with Alzheimer's to self-direct their care through the use of a surrogate.

Home and Community Based Service (HCBS) programs are intended to provide necessary assistance in meeting the unmet needs of seniors and adults with disabilities and enable the individuals to remain in the least restrictive environment. HCBS consists of two separate programs, in-home services (agency model) and consumer directed services (consumer-directed model).

Missouri's consumer directed services model gives individuals a choice regarding who delivers services and when those services are delivered. The program participant is responsible for hiring, firing, and managing individual workers. CDS could be considered another option for some families caring for a loved one with dementia. Unfortunately, individuals with dementia who are unable to self-direct their care cannot access this service delivery model in Missouri.

The Missouri Alzheimer's State Plan Task Force supports a review of other states that have implemented a CDS policy which allows a representative to act on behalf of a person with Alzheimer's who is unable to self-direct their care. Such policies should include provisions that address quality assurance, training, risk and monitoring to ensure fraud and abuse do not occur. This review should evaluate whether these CDS policies should be implemented in Missouri.

6. Connection between the National Plan and Missouri

The Task Force strongly recommends the continuation of at least annual meetings of the members of the Task Force, as well as other interested stakeholders and community members to promote statewide and community actions consistent with the goals in the National Alzheimer's Plan.

The first National Alzheimer's Plan was released in May of 2012. In support of the plan, the federal fiscal year 2013 budget includes \$100 million in additional funding for research, awareness, education and outreach, and caregiver support. A major goal of the National Alzheimer's Plan is to prevent and effectively treat Alzheimer's disease through optimizing and improving the quality of care by 2025.ⁱⁱ

To ensure the goals of the State Task Force come to fruition, as well as to promote statewide and community actions consistent with the National Plan goals, the Task Force encourages the continuation of at least annual meetings of the members of the Task Force and other interested stakeholders and community members.

ⁱ James E. Galvin, MD, MPH, Professor of Neurology and Psychiatry, Director of Clinical Operations for the Center of Excellence, Director of the Pearl Barlow Center for Memory Evaluation and Treatment, and Associate Director of the New York University Alzheimer Disease Center in New York, New York.

ⁱⁱ <http://napa.alz.org/national-alzheimers-plan>



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ALZHEIMER'S STATISTICS

In the United States, an estimated **5.4 million people** are living with Alzheimer's disease, including at least **800,000 who live alone**. Unless something is done to change the trajectory of the disease, as many as **16 million** Americans will have Alzheimer's by 2050. The cost of caring for people with Alzheimer's and other dementias is estimated to total **\$200 billion** in 2012 and is projected to increase to **\$1.1 trillion** per year (in today's dollars) by mid-century.

Number of People Aged 65 and Older with Alzheimer's by Age

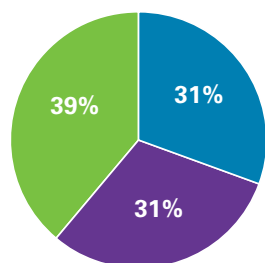
Year	65-74	75-84	85+	Total	% change from 2000
2000	6,500	55,000	48,000	110,000	
2010	5,600	53,000	55,000	110,000	0%
2020	7,200	53,000	57,000	120,000	9%
2025	8,300	63,000	58,000	130,000	18%

Number of Alzheimer's and Dementia Caregivers, Hours of Unpaid Care, and Economic Value of Care

Year	Number of Caregivers	Total Hours of Unpaid Care	Total Value of Unpaid Care	Higher Health Costs of Caregivers
2009	202,662	230,791,080	\$2,654,097,424	N/A
2010	304,448	346,705,485	\$4,136,196,441	N/A
2011	307,276	349,926,190	\$4,241,105,423	\$177,995,547

Cognitive Impairment in Nursing Home Residents, 2009

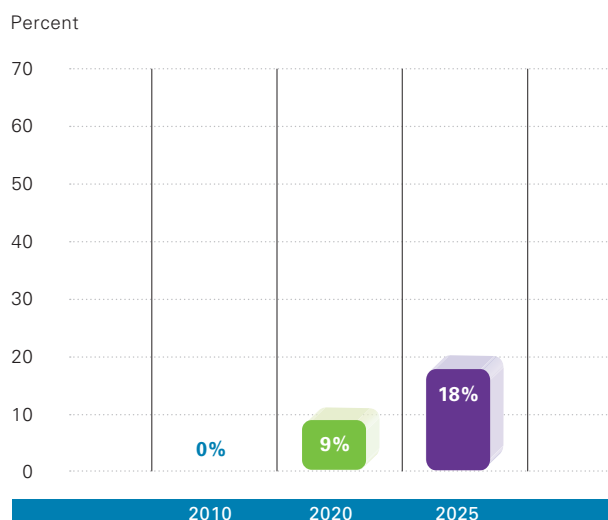
Total Nursing Home Residents **78,350**



Level of Cognitive Impairment

- severe/moderate
- mild/very mild
- none

Percentage Change in Number with Alzheimer's Disease Compared to 2000



Number of Deaths Due to Alzheimer's Disease in 2008

2,010

